

UnitedHealth Group

Advancing, Promoting and Facilitating Health

**National Health Information Infrastructure
Consumer Health Considerations
and
Recommendations for Policy**

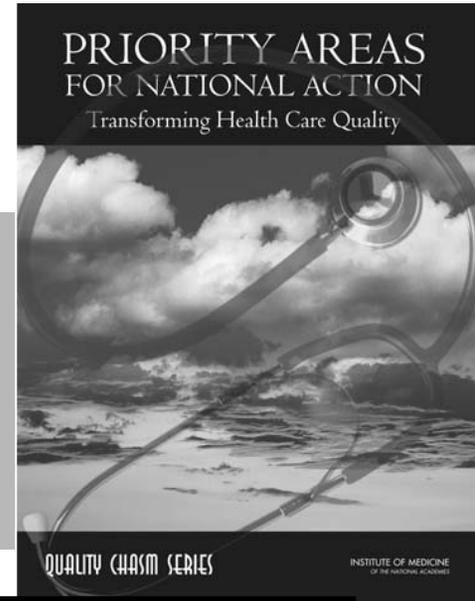
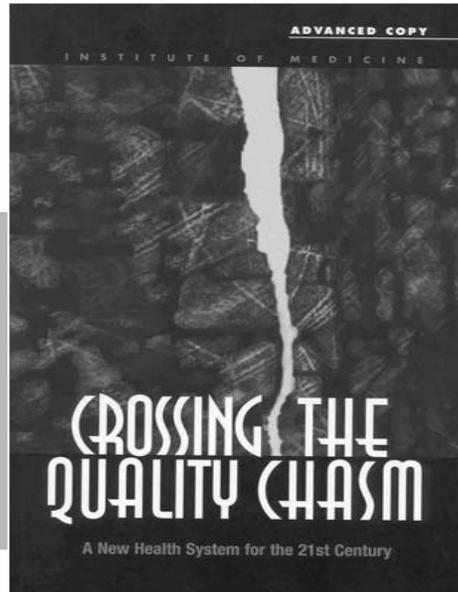
Reed V. Tuckson, M.D.

Senior Vice President, Consumer Health and Medical Care Advancement

Why it is Essential that Consumers are Served by a Robust Health Information Infrastructure

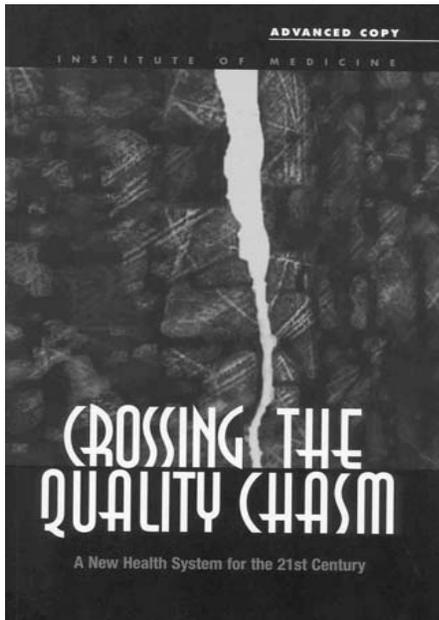
“The American health care delivery system is in need of fundamental change. The current care systems cannot do the job. Trying harder will not work. Changing systems of care will.”

“The Institute of Medicine’s Committee on Quality Health Care in America”



Health information for consumers will be a key component of that change!

According to the IOM, Consumers are Key to the Aims and Rules Necessary for Health System Reform



SIX AIMS FOR IMPROVEMENT

- Safe
- Effective
- Patient-Centered
- Timely
- Efficient
- Equitable

TEN RULES TO GUIDE THE REDESIGN OF CARE

- Continuous Healing Relationships
- Evidence Based Decisions
- Customized Care
- Patient as Source of Control
- Shared Knowledge
- Transparency
- Safety as a System Property
- Cooperation Among Clinicians
- Needs are Anticipated
- Waste is Decreased



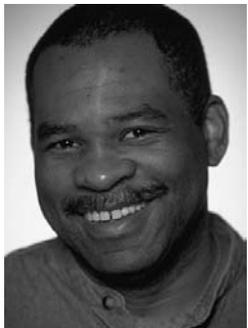
The key to all this is...

EFFECTIVE ORGANIZATIONAL SUPPORT

- Invest in Information Technology
- Coordinate Care
- Redesign Care Processes
- Manage Knowledge and Skills
- Develop Effective Multidisciplinary Teams
- Measure and Improve Performance and Outcomes

Health Consumers are a Diverse Population, Each with Different Information Needs

**Multi-ethnic
communities**



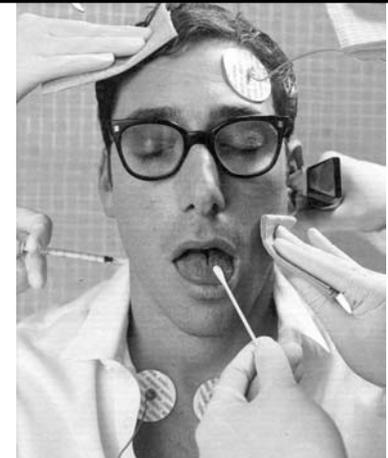
Older & chronically ill people



Women aged 24 to 50



The “worried well”



“They are segmented by their desire and capacity to seek information, their health status, and the course of their illness.”

FACCT

Why it is Essential that Consumers are Served by a Robust Health Information Infrastructure (continued)

Ready access to reliable information: there are so many more treatment decisions to be made by patients and physicians because of the explosion in the development of new scientific knowledge, pharmaceuticals and technology!

Magic in a Pill

The Food and Drug Administration has approved a pill that works as a camera to aid in the detection of problems in the small intestine. Normally, doctors use an endoscope, which is a camera-topped tube that is inserted into the gastrointestinal tract through the mouth. Unlike the camera capsule, an endoscope cannot view the entire length of the small intestine. The M2A Sval-

The new camera capsule is the size of a large vitamin.



UNITED STATES

National Library of Medicine

Site Index | Search Our Web Site

20,000 journals
17,000 new books
6,000,000 references
400,000 new entries

Welcome to the world's largest medical library and creator of MEDLINE/PubMed.

Proliferation-signature genes

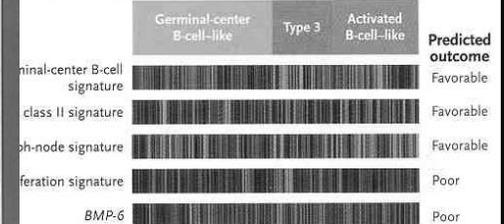


Proliferation-signature average



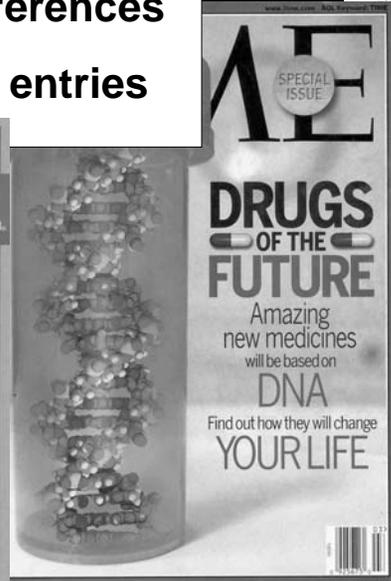
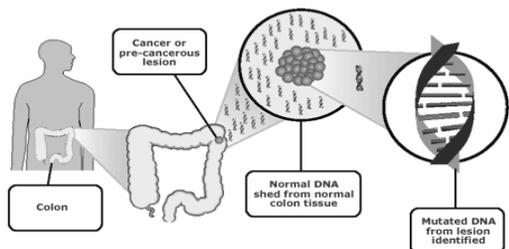
Quartile of Risk

Large-B-Cell Lymphoma—Biopsy Specimens



Low High Level of gene expression

EXACT Sciences' First Application: Early Detection of Colorectal Cancer



Why it is Essential that Consumers are Served by a Robust Health Information Infrastructure (continued)

Ready access to trustworthy information: consumers must make more health care decisions because of DTC advertising and media coverage and they have increasing expectations for access to medical care interventions and for the outcomes of care.

"I didn't know acid reflux could wear away the lining of my esophagus"

The makers of Prilosec[®] (esomeprazole) proudly introduce

Nexium[®]

(esomeprazole magnesium)

Relieve the heartburn. Heal the damage. For many, it's possible with NEXIUM.

If you suffer from persistent heartburn 2 or more days a week, even though you've treated it and changed your diet, it may be due to acid reflux disease. And that can be serious. Because, over time, acid reflux can erode or wear away the delicate lining of your esophagus (erosive esophagitis). Only a doctor can determine if you have this damage.

For many people, prescription NEXIUM—once daily—provides complete resolution of heartburn symptoms and heals damaging erosions of the esophagus caused by acid reflux disease. Your results may vary.

The new purple pill

Talk with your doctor to see if NEXIUM is right for you. Most erosions heal in 4 to 8 weeks with NEXIUM.

The most common side effects of NEXIUM and Prilosec are headache, diarrhea, and abdominal pain. Symptom relief does not rule out serious stomach conditions.

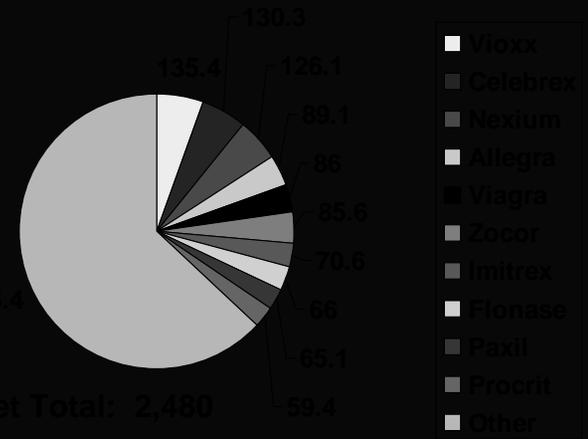
Visit purplepill.com or call 1-888-PURPLEPILL for more information.

AsinZinnica

Please read the Important Product Information about NEXIUM on the following page and discuss it with your doctor. NEXIUM is a trademark and Prilosec is a registered trademark of the AstraZeneca group of companies. © 2001 AstraZeneca LP. All rights reserved. 020101-001

Direct to Consumer Advertising

2001 Total (\$'s in millions)



Market Total: 2,480

THIS DRUG'S FOR YOU

"Everybody wants everything."

New Challenge: Internet Direct to Consumer Advertising of Medical Devices and Genetic Tests

Increasingly the Internet is used to advertise complex and expensive health care services and products directly to consumers.

“Make an Appointment for Your Ultra-fast Electron Beam Tomography Today!”

Heart and Lung Screening

EBT is a powerful tool against heart disease, but lung cancer is a growing global epidemic. No other cancer is as deadly and widespread. Every year 3.5 million people die worldwide from tobacco-related diseases - a third of them attributable to lung cancer. By 2030, that figure will climb to 10 million people. Every year, lung cancer kills more people than breast, prostate, and colorectal cancers combined. Currently, 85 percent of lung cancer victims are diagnosed in late-stage disease. [Price Information](#)



Recently, the FDA approved the use of ultra-fast Electron Beam Tomography to [accurately detect lung cancer in its earliest stages](#). Simply put, it is the best lung-screening tool in the world and makes conventional chest x-rays a thing of the past. Following a non-invasive 10-minute scan on the EBT while the patient is fully clothed, a physician or other medical professional at Vital Imaging shows the test results on a computer screen to the patient. The [heart screening](#) is also included in this test. It's like taking a virtual tour through the heart and lungs. EBT is so sensitive that even the tiniest airways can be seen with startling clarity. Afterward, a radiologist carefully reviews the test results and provides the patient and their doctor with a comprehensive written medical report. [more on lung screening](#)

SOURCE: Alliance for Lung Cancer Advocacy, Support, and Education (ALCASE)

[Make an appointment for a scan today!](#)



“Would you like to know if you have the genetic predisposition to abuse drugs and alcohol? Does your child have the genetic trait that leads to disruptive personalities?”

DOC BLUM Neutraceuticals
For The Millenium

HOME | INFORMATION | FORMULAS | TESTIMONIALS | QUESTIONS | NEWSLETTER | ORDER

DO YOU NEED HELP WITH:

ALCOHOLISM/HEROIN

COCAINE/STIMULANTS

SMOKING/TOBACCO

WEIGHT MANAGEMENT

ADHD / ADD

PMS

IMAGENE™

GENETIC TESTING FOR THE MILLENNIUM

Introducing a ground breaking addiction treatment tool.

Are you compulsive? Have you ever wondered why you crave certain things and/or act in an irrational manner? Would you like to know if you have the genetic predisposition to abuse drugs and alcohol? Are you concerned about your children's future? Does your child have the genetic trait that leads to disruptive and addictive personalities? DNA testing can help you understand and manage a child's behavior before it gets out of control.



CLICK HERE TO ORDER
IMAGENE!

Imagene will test a panel of dopaminergic related Reward Deficiency Syndrome(RDS) genes. This will allow you to know if there is a genetic predisposition towards any of the associated addictions. The Reward product line is then available to treat the genetic predisposition towards RDS.

Imagene is an at home genetic testing kit that is simple to use. Here are the actual instructions.

There are Serious Concerns with the Quality of Information Available for Consumer Decision-Making

“Misinformation and biased information leads to overuse *and* inappropriate use of drugs.”



A study from the Canadian Centre for Policy Alternatives



Drugs in the News

How well do Canadian newspapers report the good, the bad and the ugly of new prescription drugs?

- Stories often overemphasize the benefits of drugs
- Many articles don't adequately address risks
- Over 2/3 of stories did not mention side effects
- Contraindications were mentioned in 4% of cases; financial ties of these cases to manufacturers were not disclosed

HOW TO EVALUATE MEDICAL RESOURCES ON THE WEB

WOULD YOU TAKE MEDICAL ADVICE FROM YOUR NEIGHBOR'S SIXTEEN-YEAR-OLD KID?

Unfortunately, computer skills are the only qualifications needed to have medical Web sites. To get the best health care, you have to make sure that the medical information you are using from the Web is reliable and trustworthy. For the nation's top health professionals providing information from medical and patient safety experts to help you weigh the pros and cons of health information by following them, you'll be able to figure out which Web sites provide reliable information from doctors and which ones provide information from the bottom tier of the Web.



YOU MAY ALREADY HAVE.

1. Do the sites have to do several sites. Do you think a single site will provide all the information you need to know about a condition. Do you know how to find other sites if you need more?
2. Find out who owns the site. Any good health-related information is a good sign for you. Is there who is responsible for the site and its information. Do you understand the website and content of the publisher.
3. Why write the information? Is the author a physician, nurse, practitioner or other health professional? What are their credentials, education and professional experience? What are their qualifications for writing on the subject at hand?
4. What is the source of the information? Many health sites post information collected from other Web sites. If the person in charge of the site did not check the site's source, then the original source should be clearly stated and available for your assessment.
5. Medical information on the Web should be reviewed and updated on a regular basis. Do the sites have to look for current data.
6. Look to see that there is a scientific basis for the information and evidence that are offered. Look for references and information that you can learn more about the original evidence for quality of the information.
7. Look under "About this site" or "About statement" to find out the site's main purpose.
8. Do websites of sites that are not reviewed or government approved because they are mostly not for commercial reasons. The information on these sites may be accurate, but it is more to consider the possibility that someone is trying to sell something by providing the information.
9. Any credible health site asking for personal information should be clearly marked what they will and will not do with it. Be certain that you read the site's privacy policy statements, and be sure you know why they are asking you to disclose personal medical information.
10. Share the information you gather from Internet sources with your health professional. Make sure you understand their input and recommendations about your personal health issues, especially when it comes to medicine or treatment decisions.



BestTreatments 
clinical evidence for patients and doctors



Conditions Diabetes

[Home](#) > [Conditions](#) > [Diabetes index \(patient\)](#)

[Doctor version](#) 
[Printer-friendly version](#) 

More information on diabetes
[Ask the pharmacist](#) | [Personal experiences](#) | [Decision support](#)

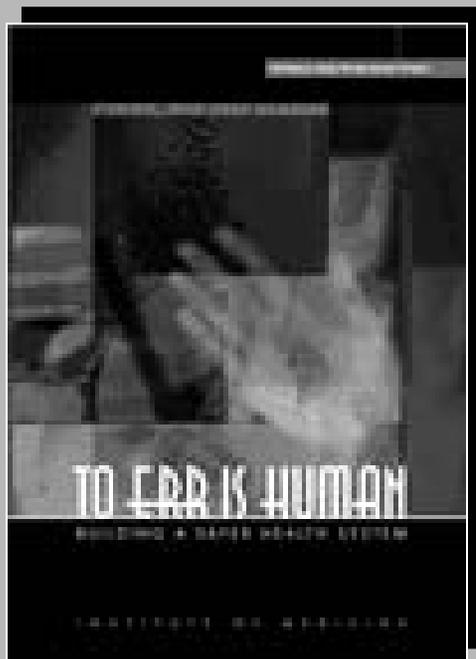
Diabetes index

If you've been diagnosed with diabetes, your life may never be the same again. Diabetes is a long-term condition that doesn't go away. And it can lead to serious health problems. But making changes to your lifestyle and taking medication can help you live a long and healthy life.

We've brought together the best research about diabetes and weighed the evidence about how to treat it. You can use our information to talk with your doctor and decide which treatments are best for you.

Why it is Essential that Consumers are Served by a Robust Health Information Infrastructure (continued)

Ready access to actionable information that can help prevent errors: consumers are increasingly attentive to the safety and quality of health care delivery.



Victim of botched transplant declared dead

Hospital: 'We very much regret these tragic circumstances'

Sunday, February 23, 2003 Posted: 1:36 PM EST (1836 GMT)

DURHAM, North Carolina (CNN) -- Doctors at Duke University Hospital declared Jessica Santillan dead at 1:25 p.m. Saturday and removed her from a respirator soon after. The 17 year-old girl had two heart and lung transplants this month, the first of which used organs with the wrong blood type.



Family spokesman Mack Mahoney visits Jessica Santillan, 17, in the hospital after her second transplant operation.

"As of approximately 5 p.m., she is no longer on a respirator," a hospital



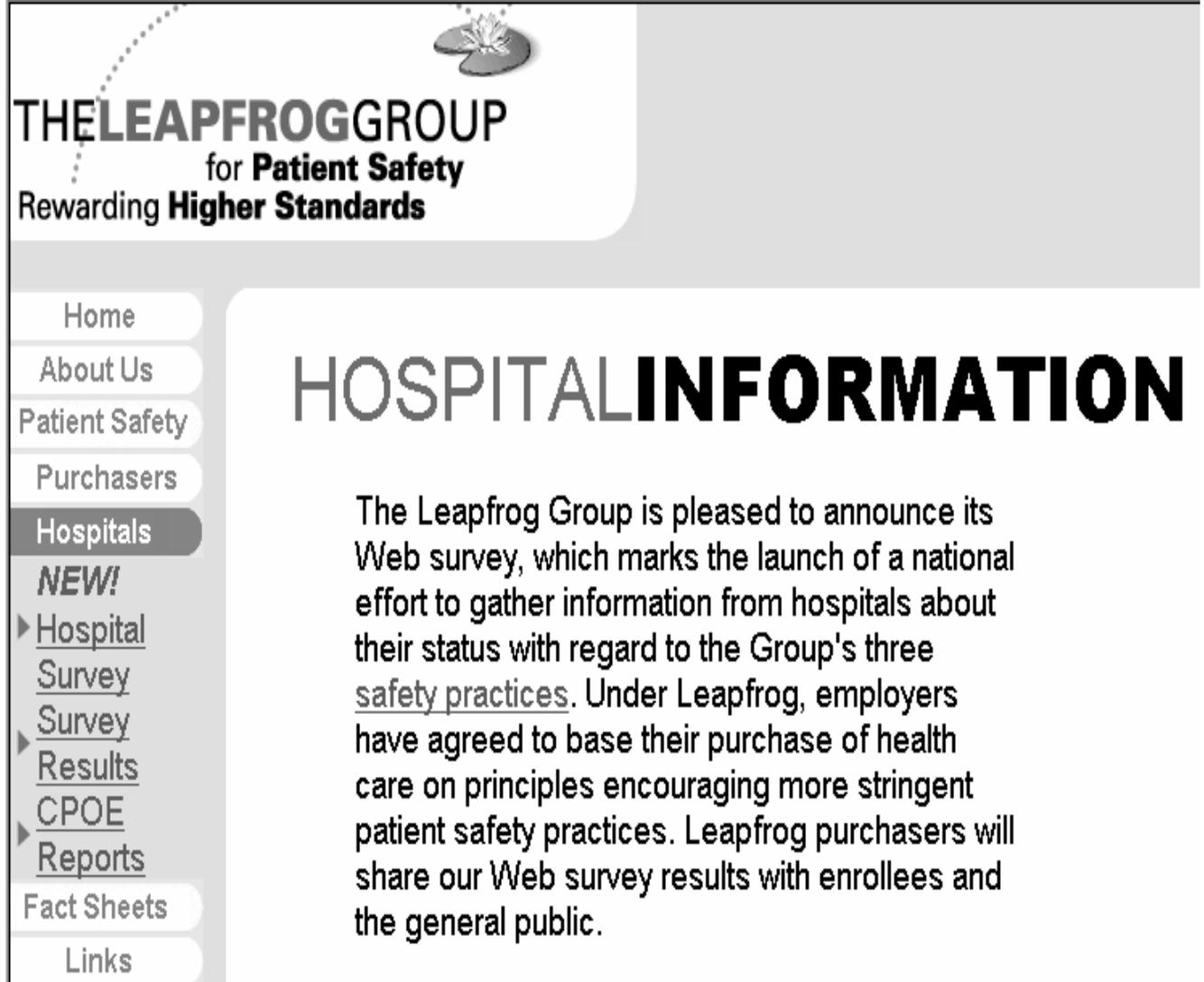
CPOE



Hospital volume for special procedures



ICU staffing by trained Intensivists



THE LEAPFROG GROUP
for **Patient Safety**
Rewarding **Higher Standards**

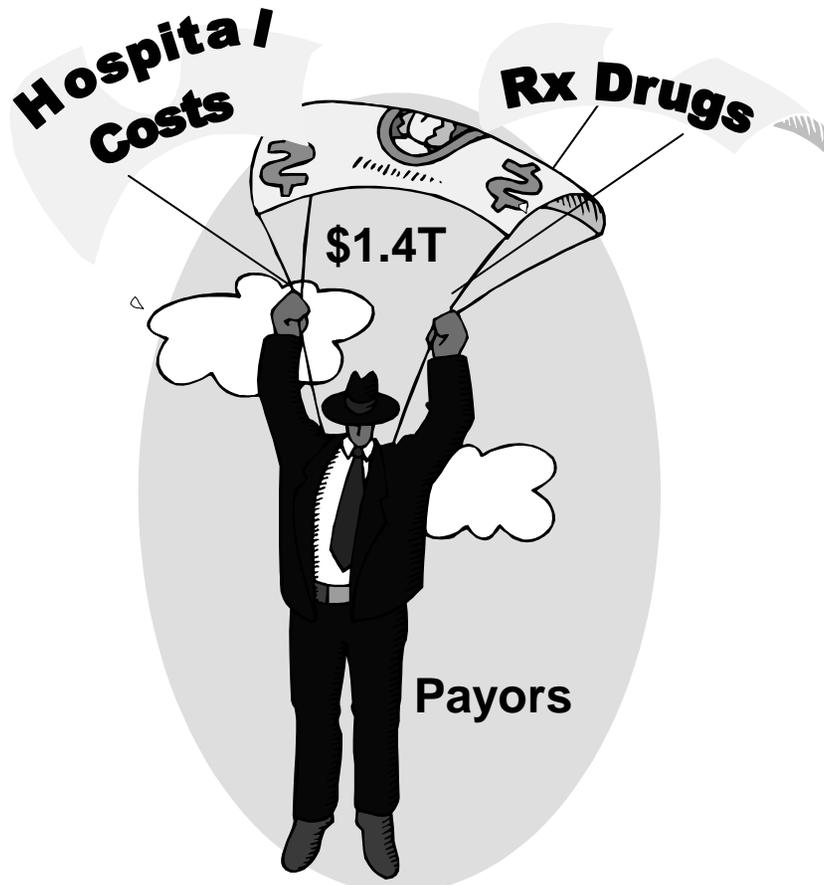
- Home
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- NEW!**
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HOSPITAL INFORMATION

The Leapfrog Group is pleased to announce its Web survey, which marks the launch of a national effort to gather information from hospitals about their status with regard to the Group's three safety practices. Under Leapfrog, employers have agreed to base their purchase of health care on principles encouraging more stringent patient safety practices. Leapfrog purchasers will share our Web survey results with enrollees and the general public.

Why it is Essential that Consumers are Served by a Robust Health Information Infrastructure (continued)

Ready access to decisionable information: consumers will be increasingly expected to make decisions that put their financial “skin in the game” as employers struggle with escalating health care costs.



The \$ bottom line

Health insurance costs fire up unions

By Julie Appleby, USA TODAY

Rapidly rising health care costs are causing strife at bargaining tables nationwide as employers seek to shift some of the burden to workers while unions battle to save benefits.



Hundreds of striking janitors and their supporters march through downtown Boston Sept. 30, 2002.

By Chitose Suzuki, AP

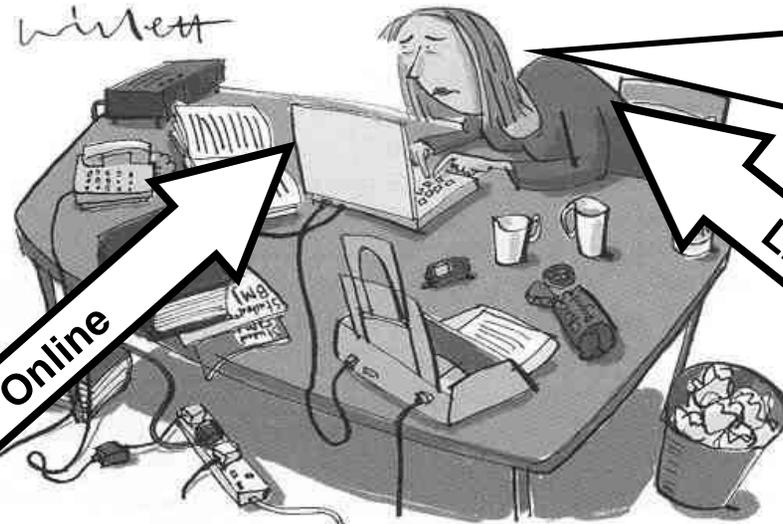
Therefore: consumers should have access to information that reliably compares the cost of care and the quality of hospitals and physicians.



The chart below summarizes the ranking of this group of hospitals for each of the measures described above. **Lower numbers are better, and the best rank in each category is highlighted in bold.** In our final calculations, more weight was given to the measures you considered most important and less weight was given to those you considered less important. This ranking would change if you had ranked the comparison measures differently.

Key Measures in Order of Importance	Covenant Medical Center	La Crosse Lutheran Hospital	Mercy Medical Center-North Iowa	St Josephs Hospital Marshfield	Wausau Hospital
Mortality Rate	1	1	1	4	5
Patient Volume	5	3	1	2	4
Unfavorable Outcomes	—	—	—	—	—
Money	2	4	5	3	1
Time	2	3	1	5	4
Weighted Average Rank:	2.33	1.67	1.00	2.33	3.33
Overall Rank:	3rd	2nd	1st	3rd	5th

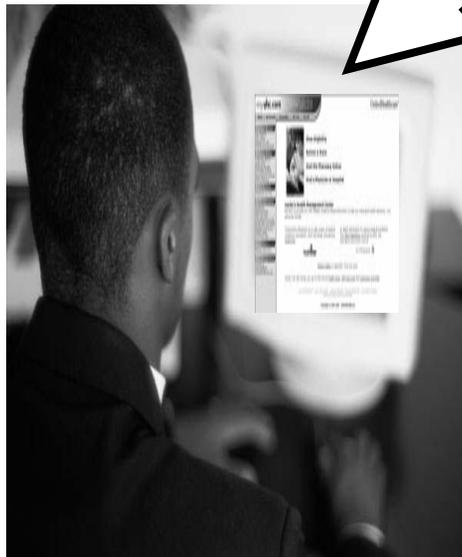
In addition: consumers should have an information infrastructure that supports them in making decisions based on reliable and trustworthy data.



I still have questions, can someone help me to make the right decisions for ME?

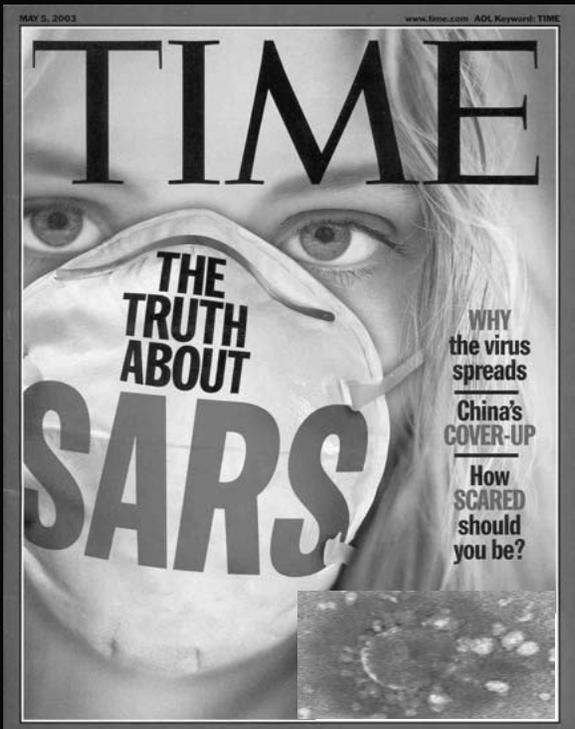
Online

Live Nurse Chat



Why it is Essential that Consumers are Served by a Robust Health Information Infrastructure (continued)

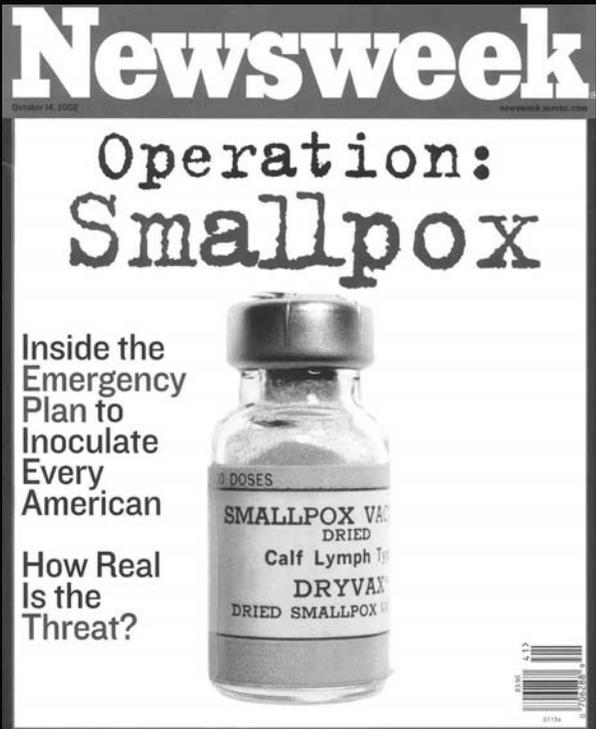
Ready access to urgent information: consumers and public health officials require “real time” access to information about biological and other related threats.



ADVISORY
Homeland Security

Current Threat Level :

HIGH



Therefore: consumer derived data should be available and used to support responsible public health analysis and information alerts.

HEALTH PLANS SEARCH FOR BIOTERROR SYMPTOMS

HOMELAND SECURITY

By MARILYN WERBER SERAFINI

NATIONAL JOURNAL 4/19/03

...in essence, the streams of data coming into health insurance plans – phone calls to nurse help lines and doctors' diagnoses - are sifted by computer programs to look for disease and symptom patterns sorted by zip code."

24-hour
'nurse line'
call in
anonymized
data

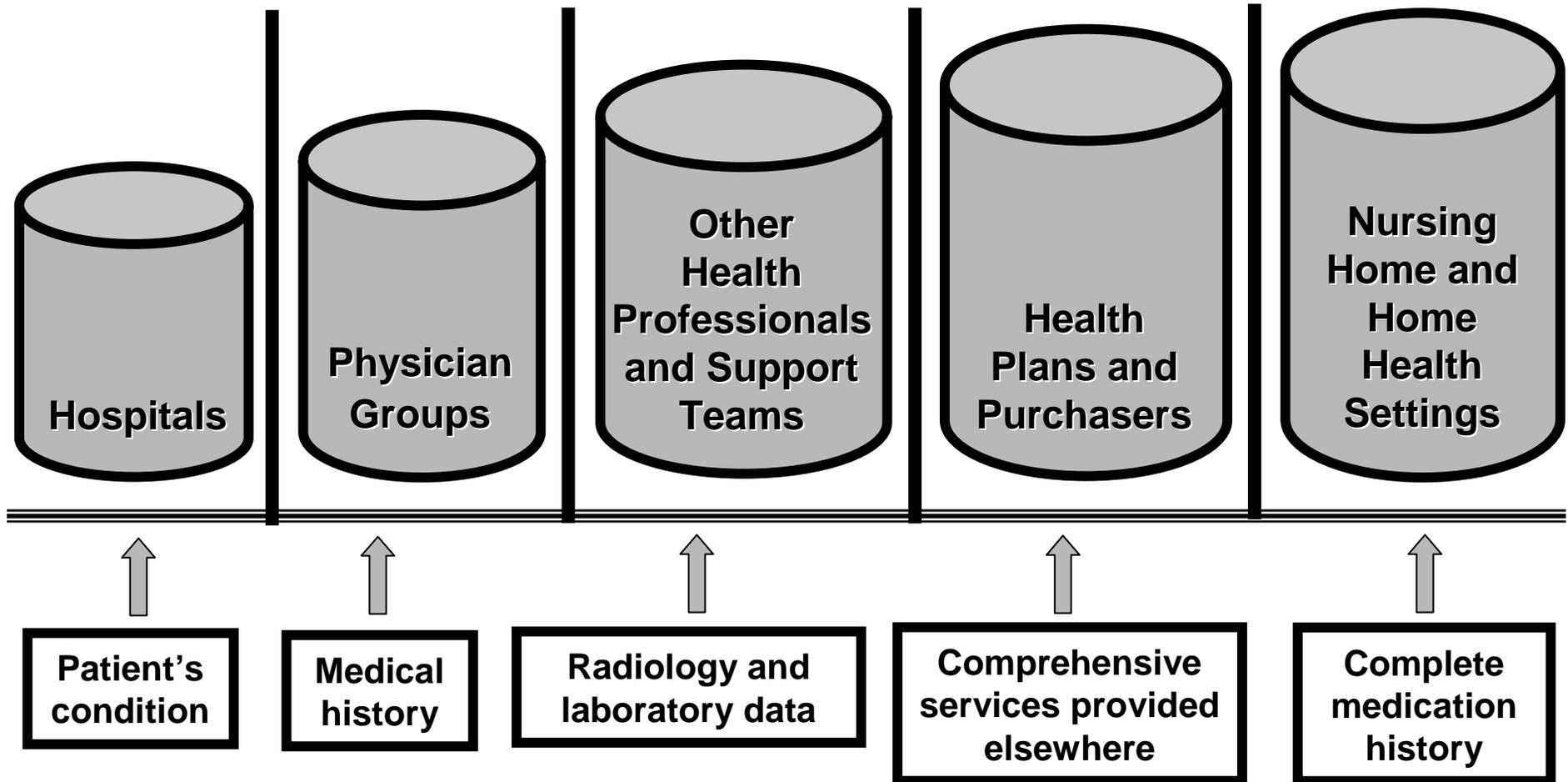
Organized by
symptoms and
demographics

Applied
against
disease
surveillance
analytics

Disseminated to
public health
agencies

Timely case
investigation

If Consumers are to be Well Served by Their Health Care Team: Information Must Flow Across Health Care Settings

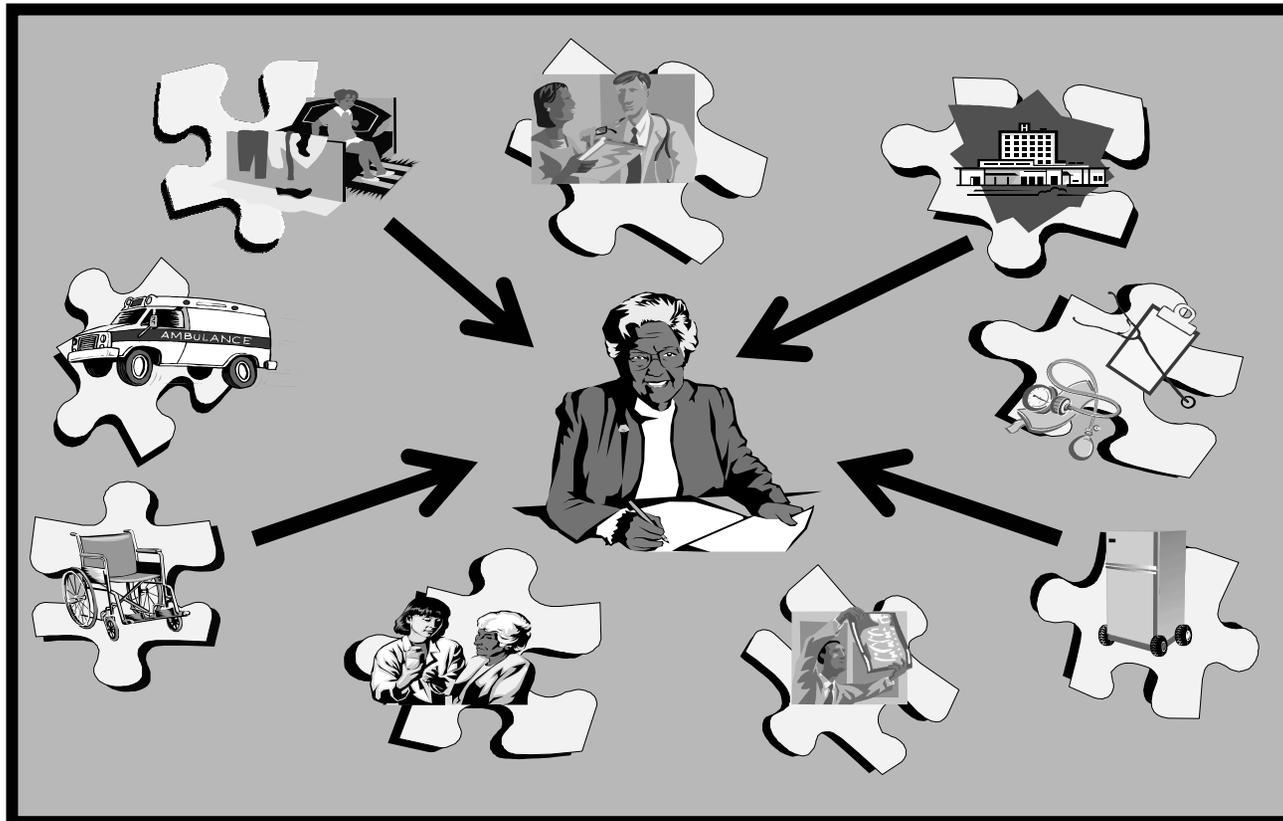


“The Health Care System is Highly Fragmented and Lacks Even Rudimentary Clinical Information Capabilities.”

Institute of Medicine

If Consumers are to be Well Served by Their Health Care Team: Information Must Flow Across Health Care Settings

This is especially important for older people and those with chronic diseases who require coordination of comprehensive medical and supportive services!



The challenge is to acquire, package, and disseminate data across health care settings as a foundation for health system change.



Why is it that this works for money and not for health care?!

If Consumers are to Participate Effectively with Their Health Care Team: They Must Have Access to Their Own Health Information

QuickStart

[Click here](#) to quickly add to your record.

My Imported Information

[Go to my imported information archives](#)

View My Records

Visits (8)

Prepare summaries for my visits with care providers.

Conditions (12)

Medications (4)

Allergies (2)

Surgeries (3)

Immunizations (7)

Tests (54)

Coverage

Health Record



Automatic alerts

This tool automatically scans for potentially harmful interactions between medications, herbs, vitamins, and allergies entered in your record.

Common Questions

How can this tool [benefit me](#)?

How is my information [kept private](#)?

How can I [print or fax](#) my records?

Save money

Did you know **30%** of your purchases can be saved by ordering online instead of at a pharmacy?

Electronic health records like this one from FACCT collect, update and integrate the conditions, tests, medications and interventions that form a person's health history.

[Home](#) [Messages](#) [Community](#) [Diary](#) [Graphs](#) [Reports](#) [Education](#) [Profile](#)

Health Record

[Visits](#) | [Conditions](#) | [Medications](#) | [Allergies](#) | [Surgeries](#) | [Immunizations](#) | [Tests](#) | [Coverage](#) | [Basics](#)

[add medication](#)

[check interactions](#)

[Health Record summary](#)

[how to](#)

Current Medications

Date▼

Frequency

Source

Click on an item to edit, delete or view related information.

[Glyburide XL 5MG Tablet SA](#)

05/30/2003

every morning

Rite-Aid

[Zyrtec 10MG Tablet](#)

05/28/2002

as needed (PRN)

Sav-on

Past Medications

Date▼

Frequency

Source

[Imitrex 20MG Nasal Spray](#)

05/30/2003

Walgreens

[Rolaids 550mg Tablet, Chewable](#)

11/05/2002

Rite-Aid

If Consumers are to Participate Effectively with Their Health Care Team: They Must be Supported in Putting Information into Action

WHEN YOU HAVE A CHRONIC ILLNESS, THERE'S NO SUCH THING AS A DUMB QUESTION.

Coping with a chronic illness can be, at times, overwhelming. So it's easy to overlook one of the simplest—and smartest—things you can do to help yourself. Ask questions.

Ask your doctors, your nurses, and therapists. Ask about your symptoms, your diet, and your treatments. Ask why you're taking your medicines and how they work.

Asking questions helps you gain information and become more involved with your own health care treatment. Questions help your providers understand your concerns, and help them do their best to help you. So write down your questions in advance. Then write down their answers.

The important thing is to ask until you understand. Remember, everyone on your health care team works for you. It's their job to answer your questions. And your right to ask.

It's your health. You call the shots.



NATIONAL HEALTH COUNCIL
For assistance or more information, visit www.NationalHealthCouncil.org or write the National Health Council at 1730 "M" Street NW, Suite 500, Washington, DC 20036-4505.

Consumers need support in taking control and using health information to interact successfully with their physicians and health care team.

WHEN IT'S YOUR HEALTH, YOU CALL THE SHOTS.

If you have a chronic illness, the health care process can be complicated and even overwhelming. That's when it helps to remember that your doctors and nurses and therapists all have one thing in common: they all work for you.

You are the captain of your health care team. All your providers are there to listen, answer your questions, and help you understand your illness and your treatments.

You can become a stronger patient by becoming a smarter one. Read up on your condition, your symptoms, your treatment and medicines. Go to the library and search the Internet. Talk with others who have your illness. Step up and take charge by learning everything you can.

The most important person on your health care team is you. If you feel strongly that you want to make a change, you can. To bring out the best efforts from your providers, you don't have to be the doctor. But you should think of yourself as the boss.

It's your health. You call the shots.



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National Health Council

The Interest of Consumers are Essential to the Design of a Robust Health Information Infrastructure

“The American health care delivery system is in need of fundamental change. The current care systems cannot do the job. Trying harder will not work. Changing systems of care will.”

“The Institute of Medicine’s Committee on Quality Health Care in America”

It is time to knock down the barriers that frustrate the flow and translation of information and data that are necessary for better quality and safer medical care decisions and outcomes.